

★
“When my baby died...”

the
lullaby
trust

Families tell their stories



Families tell their stories is a booklet published by The Lullaby Trust and written by several bereaved parents, grandparents, siblings, uncles and aunts. The Lullaby Trust would firstly like to thank them for sharing their experiences with the reader, in memory of their child. The Lullaby Trust has chosen these particular stories to illustrate the different ages and circumstances when each death occurred. We are aware that these are difficult stories to read, but despite the content, trust that the reader will be left with a feeling of hope, as each parent or relative has clearly illustrated.

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Ríoghnaich's story

Ríoghnaich died from SIDS in October 2021

Ríoghnaich was the baby I would brag about. She breastfed and slept brilliantly; she had her own wee routine within days. She loved her cuddles and being in your arms, lying on your chest lifting her head up to nose at what was going on around her. Her sister and I sang her a song; 'We love Ríoghnaich, we love Ríoghnaich, yes we do, we love you, we just love our Ríoghnaich Roo'. Ríoghnaich loved this song and always smiled when we sang it and kissed her chubby cheeks and chin.

Ríoghnaich was always engaging with you and loved being held in your arms. The more you talked or sang to her, the bigger her wee dimpled smile got. People used to comment on how they couldn't believe she was as young as she was because of her smiles and head control. She loved to watch her big sister play Gaelic football every Thursday and that is the last memory that Aoibhe has of her.

The day before she died she just wanted cuddles all day. She was rolling over, smiling and trying to laugh. I had just organised her Christening and we visited family, watched her big sister's football game, and played all night. She woke up around 3 am to be breastfed and by 4 am she was gone. And to this day we still do not understand why.

Ríoghnaich was perfect and healthy. She was happy and content. I thought if I did everything right that SIDS would never happen to her. Little did I know it still would.

Emma, Ríoghnaich's mother



Liam's story

Marcellus died in October 2022

Our baby boy was born early in 2022, after an extremely stressful pregnancy for my fiancée. He tried to come early at 23 weeks and the doctors asked us if we wanted to let him go or fight. An obvious choice for us, we chose to fight for our boy.

He was born on the 14th of February 2022 and he was absolutely gorgeous. We named him Marcellus, the Latin word for little warrior as he was just that. My daughters, his older sisters, loved him so much they screamed when we brought him home and fought over who got to hold him. He had an extremely happy life for a time – always laughing and grinning, he had the cheekiest of smiles.

He was an extremely healthy boy, however on the 23rd of October 2022 we awoke to our normal ritual, I went to get my girls from their bedroom and then proceeded to make them breakfast. While I made breakfast I heard a sound I will never forget (my fiancée screaming). I ran to the baby's room as fast as I could and when I came into the room my heart shattered, our baby had lost all colour in his skin and there was no cry aside from my fiancée and myself. No laughs, no smiles, my little boy had stopped breathing.

I called emergency services as quickly as I could and while awaiting an ambulance I was instructed how to give my little warrior mouth to mouth and attempt to resuscitate him. The ambulance arrived and quickly took action, they did everything they could but he wasn't breathing. They rushed him to the hospital and we followed quickly behind. When we walked through the doors of his hospital room we were met with many doctors and nurses and they told us "We have tried our best and he is a fighter but he is unfortunately not going to win this time". My fiancée screamed and cried and the only two words I could get out were "my boy" and we held our poor beautiful baby boy for the last time. His body was cold and lifeless and the doctors told us and repeated to us that it was nothing that we had done and that it was SIDS. We broke.

In the next coming weeks, I'm constantly thinking of a quote I once read "In peace sons bury their fathers, in war fathers bury their sons." This is the most unnatural thing any parent can go through. We have so many regrets

and self-blame moments, we know it wasn't our fault, but the pain and fear will forever scar us. No parent should ever go through this pain and no child should be taken from the world with no explanation. This is our story.

Liam, Marcellus's father



Forever in our hearts

Lola died in September 2008, aged 5 ½ months

Lola Jane was born on the 8th April 2008. She was our 3rd child. Unlike her brothers Stanley and Frankie, she was born a week late. The week she was due we had heavy snow but the week she was born we had beautiful sunshine.

I remember the first time the boys bounced into the hospital to see her, "Wow a baby girl, we've got a sister". Within a few weeks, she had gained a wardrobe bursting with beautiful pink clothes, ironically looking back most of which had a symbol of butterflies on.

The next few months she settled in home well. Stanley (then 5) and Frankie (then 4) doted on her, they would bathe with her, feed her, her bottle and even help with the nappies. Summer came and Lola loved being outside, whether in the garden overseeing the boys playing football or feeding the ducks in the park. More than most she loved nothing more than greeting the boys in the playground after school. Smiles and laughter all round. They were so proud of her.

The day before was Saturday 20th September, I had gone back to work for the first time leaving Lola with her dad, Jason and the boys. They spent the morning at Soccer School and the afternoon was spent in the park and at a school friend's party. That evening was my mum's 60th birthday party, Lola met the rest of the family who had not yet met her. She was normally in bed by 8 pm so I wasn't surprised when she fell asleep in my auntie's arms. She woke at 11.30 pm and I gave her a bottle and put her in her car seat ready for home. We were all in bed by midnight.

After all sleeping well, I woke at 8 am on 21st September to silence which felt strange! I walked into her bedroom to see Lola was face down on her tummy, with no movement. I just froze and screamed running away from her room, "NO, NO, NO" I shouted. Jason ran into the room and picked her up carrying her into the front room. We rang 999 and started CPR, within 10 minutes two rapid response cars had arrived followed by an ambulance. The paramedics tried to resuscitate her without success then she was rushed into the ambulance and taken to hospital. After further attempts to resuscitate her, the paediatric nurse told us that she had passed away.

The next few hours we were in total shock, family members were arriving at the hospital and the police had arrived and taken our house keys off us. Was this a bad dream? They explained to us they were to visit the house and would return our keys to us then we could return. They did this and gave us some leaflets on The Foundation for the Study of Infant Deaths (FSID- now The Lullaby Trust).

The hospital couldn't tell us how she had died, and this we found so frustrating, as our oldest son Stanley had a cardiac arrest at 6 months old. Luckily for us, we were in the best place at the right time, which was the Royal Brompton and Harefield Hospital, having been admitted earlier in the day with SVT. He had emergency open heart surgery and was put on Echmo, inevitably spending the next month on life support. He made a full recovery and remains healthy today. However, I was convinced Lola and Stanley's condition were linked. The post-mortem results showed Lola had died from the bacterial infection, Group A Streptococcal Septicemia. Further tests from the Royal Brompton proved inconclusive.

Lola's funeral was on the 13th October and there were so many friends and family there, which was so comforting. Everyone wore an item of pink clothing and had a butterfly attached, there were so many flowers it was surreal. We chose the songs Somewhere over the Rainbow, which felt appropriate and Take That's, Rule the World which reminded us so much of her.

The next few weeks were so painful and I eventually picked up the leaflet from FSID. I needed someone to talk to outside of the family, to make sense of it all. I gave them a ring and the continued support and advice, I have received, has really helped me in some way to come to terms with our loss.

Jason has since done the London Marathon and I have done the Great South Run as well as numerous other events with our friends and families to raise funds for such a wonderful cause.

On the 14th December 2009, Lola's little brother Freddie was born. Lola will always be in with us. The five and a half months we spent with her left us with such great memories of such a beautiful happy girl, who brought so much love and laughter into our lives, which will be cherished forever after.

Suzanne, Lola's mother



My beautiful grandson had gone

Joshua died in February 2006, aged nearly 5 months

On 19 September 2005, my eldest child Tanya went into hospital to have her labour induced. It was her first baby. I was so excited. She had asked me to be her birth partner, along with her fiancé Lee. I was over the moon and felt extremely honoured. The thought of seeing my first grandchild being born was a bit scary. I wasn't sure how I was going to cope with seeing my little girl going through the pain of childbirth. I knew it was going to be difficult yet the most amazing experience of my life, one I wouldn't have missed for the world.

Joshua arrived in only three hours and was absolutely gorgeous. I loved him instantly. He was my grandson and I was so proud of him. I couldn't wait to show him off! I took photos, lots of photos, from every angle, every expression.

On 14 February 2006, my husband Paul, Tanya, Lee and I decided to go out for a Valentine's meal together. We were only out for an hour and a half because Tanya and Lee didn't like to go out and leave Joshua for long. He stayed at home with his great-nanny and his uncles. When we got back Lee went home as he was working the following day. Tanya intended to leave Joshua with me the next day, as she was decorating their new flat so they both were going to stay the night.

At ten o'clock Tanya went up to get Joshua from his travel cot for his last feed. He was lovely at that time of night – all smiles. That was the moment that our world fell apart. I can still hear Tanya screaming now. "Mum, my baby is dead. Help me. My baby is dead!" Then it was sheer panic. I remember seeing her holding Joshua at the top of the stairs and I knew it was true. The terror on her face said it all. She was looking at me with pleading eyes like I should do something. After all, that's what mums do, isn't it? They make it all better. Except this time it wasn't going to happen. I didn't know what to do. I felt useless.

I started mouth-to-mouth, trying to follow the instructions I was being given over the phone. It wasn't working. He was just lifeless. It went on for what seemed like forever until the ambulance men arrived. I can remember thinking that this is not real. It must be a nightmare. Everyone was so happy

five minutes ago and, in an instant, everything just changed, forever. We followed the paramedics to the hospital and Joshua was rushed off. After a short while, Tanya was told that they should stop trying to revive Joshua.

They needed her permission to stop.

We were taken in to see him – my grandson. He was just lying there, with all these machines all around him. My beautiful grandson had gone. Lee arrived at the hospital knowing nothing except he had to get there quickly. After all, no one could tell him over the phone that his son had died. How do you tell someone that?

The days and weeks that followed were a bit of a blur. I found it really hard to see my child in so much pain. Childbirth was nothing compared to the pain I had to watch her endure after Joshua died. I would have done anything to have taken the pain away, as any parent would. All she wanted to do was hold her baby. She didn't want anybody else.

Something I find hard to deal with is the feeling that I have lost my own son. I am grieving like he was mine. Well, he was, he was my grandson. Then I feel guilty because if I feel like this, then what on earth are my daughter and Lee feeling like? After all, he was their baby. I have to be strong for them but it seems like they are strong for me! Is that right?

Joshua's picture sits on my lounge wall, in pride of place, larger than life, and is a constant reminder of exactly how precious he was. I get comfort from his pictures and am glad that I took so many pictures of him. It's all we have now.

I hope one day that I will overcome my fear of this happening again so that my grandchildren will be able to pack their bags and come to stay with nanny and granddaddy again. For now, though, I feel as if I have been robbed.

Linda, Joshua's grandmother

I didn't have anyone to share my burden with

Martin died in August 1990, aged 3 months

When I lost Martin, I really did feel that the end of my world had come. I remember sitting in my GP's surgery and being given FSID (now The Lullaby Trust) leaflet depicting the couple on the front. I felt really insulted and very isolated, as if all single parents were being looked down on. At that moment I did not feel inclined to use the Foundation for support.

One of the things that I found when my baby was alive was how intense my love for him was. Without belittling couples, I feel it is harder to bear the death because your love for the baby is so condensed and solely for the baby. You are not sharing your baby with anybody and you feel extremely overprotective, so understandably the grief is even harder to bear.

I was lucky to have an understanding doctor who insisted on seeing me once a week. I became quite ill so he referred me to a psychologist. At the beginning of my therapy, I felt that I was losing my mind. Now I believe that was because I had to bottle up my grief and I didn't have anybody to share my burden with. Whenever I saw the psychologist she encouraged me to talk, talk, talk and then I would end up crying. But it was the release that I needed.

It would have been really helpful if I could have had some advice from another single mum. For single parents especially, a Helpline could be their only sanctuary when it's late at night or first thing in the morning.

It is important to get somebody to help you with the horrible parts before the funeral. I was fortunate that Martin's coroner cared enough to exceed his duties. When you're a single parent the prospect of paying for your child's funeral can seem horrendous. Fortunately, my funeral director didn't charge me for Martin's coffin or the first car, so in the end, I had a relatively small bill, and this was paid by the DSS. I would never have known that the DSS could contribute to funeral costs if you're on sickness benefit. Luckily my mother worked for Social Services and she told me.

The hardest part of coming to terms with Martin's death was the aftermath of the funeral. Coming back home, my two-bedroom flat seemed like a mansion without him.

In the beginning when I could not sleep, I would go into the spare room and push Martin's pram back and forth. I did that for what seemed like an eternity – I never knew why – but when I eventually sold his pram, it was the biggest wrench to sever the final tie.

I was very lucky to have good friends whom I could lean on for support. However, I found that I couldn't talk to my parents about how I was feeling. I knew they had the burden of their own grief. When I needed to offload, my grandmother was there to help.

My family and I have come a long way since that dreadful night three years ago. We still talk together about how much joy Martin brought with him in the short time he was here. He was a contented little boy who brought a ray of sunshine into our lives.

Debbie, Martin's mother

Laura's story

Grace died June 2016, aged 10 weeks

On the day that Grace was due her jabs, she fell asleep while I breastfed her on our bed. As she was getting her vaccines that day I thought I'd let her get more sleep, so I left her upstairs whilst I got her brother Robert's breakfast ready.

It was the one and only time we changed her sleep routine. We would usually bring her with us to sleep in the same room we were in, but this time I didn't want to disturb her.

Something was bothering me and so, when I went back upstairs to check on her my worst fears were coming true. I found she had rolled over onto her face and wasn't breathing. I picked her up, she was all floppy and ran downstairs. I began resuscitating her myself whilst waiting for the ambulance.

Our neighbours got home as the emergency services arrived and looked after Robert for us. Everything that could have been done to save her was attempted, but despite having all the specialist care in two hospitals none of it could change the eventual outcome.

On the 7th June 2016, Grace died.

Originally there was some confusion regarding the cause of her death. We were first informed Grace had tested positive for pertussis (whooping cough) but that was a serious admin error. We were then told she had died of SIDS and eventually, after receiving the results of the post-mortem we were able to talk through the results with a specialist and ask them the questions that we had.

The first line of the post-mortem read: 'Grace was a well grown well cared for baby'. It is so hard to know she died of SIDS as she was perfectly healthy otherwise.

Going through this admin error was awful. At first, we had an answer, some explanation for why Grace was gone but then suddenly that reason was taken away from us. It felt like we began the whole grieving process twice.

We received a formal letter of apology, but I just wanted to know if they would change their system so it could never happen to other parents.

I'm thankful that my husband was at home with me that day. I'm needle-phobic and needed his support to get through Grace's immunisations otherwise I would have been on my own that day. We also had a close group of friends, with children of similar ages, in the village. We attended the village church where the congregation was extremely supportive.

One day not long after Grace's death, my husband Barry had to go back to work. I felt like I had no one and I felt like I was going crazy. I took Robert out to try and find someone, anyone I knew but my neighbours weren't home. I didn't know where to turn. I then called The Lullaby Trust helpline and someone kindly put me in touch with a Befriender. I remember verbally throwing out every emotion down the phone and telling the whole horrid story. She listened and said a little bit about her own circumstance. I remember her baby only being a few days old but not much more. At that moment I really needed someone and someone was there.

Laura, Grace's mother



Chloe was like my little sister


Chloe died in December 2001, aged 2 years

I was only nine years old when Chloe died. It was the 16th December 2001. I remember my older sister, Sharon, had phoned earlier in the day to say when they were coming up for Christmas. Sharon, Chloe and Nick (Sharon's partner) had moved down to live in Wales. They had lived with us before so Chloe was like my little sister, she always came with us on holiday and I always remember her meeting me from school.

When Sharon phoned on that Sunday, Mum was dressing my brother James and me up as shepherds for the nativity play. We had dressing gowns and tea towels on our heads! We had done the play and went back home. We had just got a computer so me and James went to play on it. I remember Mum coming up and saying we had to go down to Sharon's straight away as Chloe had gone to the hospital.

We all got in the car, including our dog and drove for what seemed hours and hours to the hospital in Swansea. None of us talked much and when we got there Sharon was crying. I remember going into the room in the hospital and seeing Chloe, she was lying on a bed wrapped up in a blanket. She just looked asleep. I remember James tickled her feet that were sticking out of the blanket to wake her up but of course, she didn't. After what seemed like ages Gary, my older brother carried Chloe to another room that had a little bed and teddies sat on it. We had to leave Chloe there. I now realise this was the chapel of rest.

We all went back to Sharon's house and slept on her floor. It felt strange seeing all Chloe's things but she wasn't there. After a few days, we came back home and then it was Christmas but none of us wanted to have Christmas that year. I had to go back to school and everyone was very kind. Chloe was



buried back in our village churchyard six weeks later but I know we all felt it was forever.

We still have lots of photos of Chloe that are of course very precious. One is of her sitting on the slide in our garden with a very cheeky grin on her face, which is how I remember her. James always remembers when he used to have lines of cars going across our floor and Chloe used to try and move them and put them out of line. He used to get very cross and she would laugh at him and run (or toddle!) away!

We will never forget Chloe.

Mark, Chloe's uncle

Our first grandson

Bailey died in February 2010, aged 24 weeks

Bailey Ian Jenkins born 15th August 2009 did not wake 1st February 2010. Reason: sudden infant death syndrome (commonly known as cot death).

As a grandfather you do not expect to lose your own children let alone a grandchild. When my daughter rang me at 1 am to say that she had discovered Bailey (Bubba to us) not breathing we went straight to her.

It took us less than 2 minutes to get there, we tried to revive him, and the police and paramedics took over. They took Bubba to the hospital with his mum and dad.

The not knowing feeling of why or how it happened- a child one minute full of life and just starting to get his own little personality, always laughing and smiling. He was my daughter's third child, her first son, our first grandson.

The last time I can remember hearing about cot deaths was when Anne Diamond lost her child - I did not think that this could happen to one of my grandchildren. When we received the word from the hospital that Bailey was gone it was like there was no reason to live. What was the point of a child just going to sleep and not waking? It's not as if he was ill. It's not as if we had any chance to say our goodbyes before he left his mum and dad.

I know that if Bubba had been ill we might have been prepared for the loss but there was no reason. There were no signs. There was just a sudden feeling of emptiness. The no reason, the no answer to the only question- WHY?

The police were treating the house as a crime scene. We were not allowed to go into Bailey's room. We were not allowed to go upstairs without the police. It felt as if we had been found guilty of a crime and not as if we had just lost a child. But the child protection police, after they had done their job, told us they understood our grief and were only having to do their job. They took everything of Bailey's, bed, blankets etc, they took all the tablets etc belonging to my daughter and her husband. Their reason: just in case. What does that mean? It took days, no weeks for them to say no foul play. They were nice about it I think... I had tried CPR on Bailey. I know I marked

his chest and mouth. I told the police it was me who marked him, not my daughter. I was worried, thinking they might blame her for the marks but they told us they knew that this does happen. It was then they said they believed it was just a cot death.

Cot Death - no reason. Just go to sleep and don't wake up. How do you get over this happening? Time is a great healer they say. I am 65 and know that it's not a healer but as time goes by it does become easier. You never forget. How do you comfort someone after such a thing? What do you do?

My family remembers Bubba in everything we do. We had a birthday party for him. My daughter and family named a star for him, they all say good night to him and good morning to him when they wake. We know he is not here but we all know he is in our hearts and that is important. My daughter is due a baby in December. We know it's a girl. The hospital and our doctors have been fantastic and have taken great care of my daughter. Some fools have said that she is replacing Bubba but this is stupid. You cannot replace a child. Any mother and father know that each child is different no matter how old they are.

How do grandparents cope with the loss? What do we do? It's not our child! NO, but it is our child's loss. It's hard to watch someone who has grown into an adult hurt so much you cannot take the pain away. You cannot say any magic words. You cannot rub it out and start all over again, you just have to be there for them that's all. Be there when they need a hug, when they are angry when they need a friend. How have I coped as a grandparent?

We have three granddaughters- all little dreams, they help. But I found that by keeping Bailey's memory alive, by trying to make others aware and by fundraising, this has made the hurt easier. Trying to get other parents to see that with care and attention, this may not happen to them. I know that in some cases nothing can prevent it but maybe someday, somewhere they can find a reason and a cause and be able to prevent it. IF ONLY.

Brian, Bailey's grandfather

Running for Sidney

Sidney died in December 2009, aged 13 months


When my beautiful son Sidney was born, on 7 November 2008, it was as if all our family's dreams had come true. Our only child, Betsy, was 10 but for six years my husband Ben and I had been trying for another baby through IVF. Miraculously, the second we decided to stop, I became pregnant.

Everyone was overjoyed, our new baby was like a little doll, with enormous blue eyes, blonde hair. His big sister was like a second mummy to him. I remember saying to Ben that he looked too perfect.

He was always an extremely smiley, contented boy who had so much love to give. At a year he was chatting away and starting to walk, but just after his first birthday, a week before Christmas, he got a cough and a cold, which kept him awake all night. We had the steamer going in his room and when he finally fell asleep we were really hoping that a good rest would help him to get better.

The next morning Ben brought me a cup of tea and went in to check on Sidney. I heard a scream. It was clear that our boy had died but he just looked asleep and so peaceful. The emergency services arrived and after that, I only remember the day in flashes. Much later on, we were told that he had experienced an overwhelming infection, which was too much for his little body to take.

The most powerful memory I have of that horrifying day is how wonderfully sympathetic everyone was. Strangers were just phenomenal. They didn't know us but they were all visibly shaken. The Ambulance man, who was the first to arrive at our house, was fighting back tears and when we got to A&E a young punky-looking medic had to keep biting her lip, she was so upset. Later on, we were supported by the hospital's lovely chaplain and an amazing bereavement nurse called Sara. I just don't know how they do their jobs. We're so very grateful to them.



Two days after we returned home, Betsy answered the door to two uniformed police officers. At first I was shocked until they produced an enormous bunch of lilies paid for by their team. One of the officers told us how he had lost his young brother when he was only 12 and Sidney's death had moved him so much that he felt he had to visit.

It's been so incredibly hard coming to terms with this tragedy. I remember ringing the Samaritans in desperation at 1 am and I've been having counselling, but I spend at least 40 minutes of my session crying. Bereavement support has helped Betsy enormously. At the moment, Ben, Betsy and I are trying to choose words for Sidney's headstone. We're also about to go on our first holiday without him.

Channelling our energies into fundraising has given us and members of our family some comfort and our son was such a special person, he deserves to be remembered.

I'm running the British 10k for Sidney. The thought of running that distance makes me feel quite sick. However, knowing that I'm going to do this as a tribute to my son and to raise money for a great charity which is researching infant death and helping other people in my situation will keep me going. I might not finish until Monday but I will finish.

Amanda, Sidney's mother

What we had was so special

Milo George died in November 2008, aged 8 weeks

The 6th November has always been an important date for my wife and I. We started our relationship as 16 year olds on the 6th November and then seven years later were married on the 6th November. This particular year our anniversary fell on a weeknight (always a nuisance) but luckily coincided with the grand opening of Christmas shopping hours in the shopping mall in Norwich. So we thought we'd take the kids (Isaac our oldest and Milo) to the mall for a pizza and to see the lights and Santa.

After eating and strolling around the mall, having checked Milo in the pushchair several times throughout the evening (he was a very sleepy baby, so him sleeping the evening away was not unusual) my wife checked him again and found him to be unresponsive. Thankfully my brother and sister-in-law were with us to whip Isaac away and ensure he didn't see what was going on while I grabbed Milo, laid him on a bench in the mall and called for help.

To this day it still warms my heart to think of the number of people who stopped and volunteered to help that evening. Within seconds there were two community first responders with us and the ambulance was on the way. After 20 minutes in the mall and en route to the hospital, then another 20 minutes at the hospital, we lost our Milo man.

I remember thinking at the time that things would never be the same again. That we would always be stigmatised as the "people whose baby died". People would always question our parenting ability. To some extent I was right. Things have never been the same, but that's not to say things are worse for us. We have bad memories, but we have 8 weeks of fantastic memories too, which is more than some families ever have. In his short life Milo George brought us so much happiness and joy – surely we can't allow ourselves to forget that and mope over him instead? Do people question our parenting or stay away from us because we've lost a child? No. Anyone who means anything to us knows that our lives revolve around our children, anyone else doesn't matter.

I don't think time heals because we forget, but I believe that we become better at dealing with what's happened as time goes on. That said there are

still times (fairly regularly if the truth is known), when my wife and I struggle emotionally and need to take some time out to compose ourselves. Secretly we both love these times. It sounds weird, I know, but I would hate myself if I didn't think about Milo every day and spend time talking about him with family and friends. He is still Isaac's little brother and our son – our memories of him can never be lost or taken from us. If they make us hurt a little bit or cry occasionally, I think that's a small price to pay and he's more than worth it!

Having said all that, generally, my wife and I (along with our families) have opted to take a positive approach to this tragedy. In the year after Milo died we arranged a dinner dance event on the first anniversary of Milo's death and my brother and I ran the London Marathon, all to raise money for FSID (now The Lullaby Trust). In 2009/10 we raised over £13,000 for the charity. This year we hosted another smaller event and raised over £1,300 on the night alone. Hopefully, this will become an annual event in memory of our little man.

While I would love to spend more time fundraising for the charity, life is busy. We have a little girl Melia Belle, who is now 7 months old and threatening to crawl backwards more every day. Isaac is nearly 4 now and still fondly remembers his brother but has never been affected negatively by his loss. We have been careful with the words we've used in front of him, but have never avoided talking about Milo nor have we hidden our tears from him. Isaac is always involved with visiting Milo's grave and celebrating his birthday and while he doesn't really understand the gravity of the occasion he is interested in why his brother died and has made links between Milo and Melia. It's hard but it's just something we have to deal with.

Overall, we feel blessed to have been able to spend some time with Milo, we will miss him always, and cry frequently, but that's ok, the pain only reminds us that what we had was so special.

Gareth, Milo's father

Lucky to have had her, even for a short time

Karma died in December 2007, aged 11 weeks

On the 20th of September 2007, I gave birth to my first child at the age of 18, a beautiful girl called Karma. She was a healthy baby and my partner and I had planned to have her- we were really excited to be parents.

On the 7th of December I had arranged to go out, so Anthoney and I left Karma with my sister, who was a great support to me as a young mum. We returned at 6 am to collect Karma- she was only 11 weeks old so I was still too nervous to be away from her overnight. When we arrived home with Karma I gave her her morning feed. We loved watching her smile; she was so bright and happy in the morning. We laughed as she made funny noises.

At 8 am we all went to bed, Karma slept in her own bed in the same room as us. Although we were in temporary housing at the time the house was in the best of conditions and was clean and maintained. Only 2 hours after falling asleep, I woke up suddenly feeling anxious. I had no idea why but I quickly turned my head to look over to Karma's bed and she was not in the position I left her in. I jumped up and screamed waking Anthoney. I picked Karma up and she felt warm but I could feel she was still. I kissed her and put my finger on her to see if she was breathing, I hoped I was being dramatic but I was right, she wasn't breathing. My heart sank.

My partner was panicking and I knew I just had to stay focused. I had done first aid training so tried to resuscitate her. I was so scared I was going to make a mistake so I told my partner to call 999. The ambulance came in and began to try to resuscitate her. They asked me questions, which I knew were necessary but felt intrusive. It was the most terrifying thing, not being able to do anything and not knowing if Karma was going to live.

The paramedics took her to hospital and after only a short time the doctor came to tell us that nothing was working and maybe it was time to give up. Determined this was not going to happen to us, to our daughter, I begged him to continue. Eventually, Karma began breathing but we were told it was mainly due to the numerous adrenaline shots she had been given and because she had been unconscious for so long there was a high risk of brain damage. I started to think of how my life was going to change if Karma did have brain damage but that I would be happy to have her no matter what.

The Children's Acute Transport Service (CATS) arrived by helicopter to assist and fly Karma to Great Ormond Street Hospital; if she became stable she would need intensive care immediately but unfortunately, Karma was reliant on a machine. This was the point at which my partner and I had to make the decision to let her go. I remember thinking somewhere out there was another mother in the same pain as me, praying and hoping her child could be saved, but I knew mine couldn't and I felt selfish letting the CATS team stay there any longer when they could have the chance to help or save another family. We held her and said our goodbyes and she died.

In the numb days afterward we were referred to The Lullaby Trust for help, although we had no idea at this point why Karma had died. After the autopsy, it was heard that Karma was a healthy baby and the cause of death was sudden infant death syndrome (SIDS). I had lost my daughter and lost my identity as a mother and it was even worse knowing that her death could not be explained.

Within the year following Karma's death, I slowly began to grieve and I dealt with her death by going to college and working in a nursery. One day I felt down and called The Lullaby Trust where I spoke to Marcia and it was so helpful just to speak to someone who had no idea of my life or situation and could just listen. At times I wouldn't even say much, I'd just think or cry. I only called twice as I felt that was all I needed- as I had my mum and sister – but at times I felt as though I didn't want to upset them, so being able to call The Lullaby Trust really helped.

A few years ago I decided I wanted to become more involved with those who had lost a child. I went to a Lullaby Trust Family Day and after meeting other parents I knew I had to get involved. I had just started University and now had a two-year-old boy so was very busy, but I wanted to contribute. It was suggested I become a Befriender and after training I found it to be a rewarding involvement. I am glad that I can support other families, especially young mothers, through such a difficult time. We will always love and miss our daughter Karma Nai, she was a lovely baby and we are lucky to have had her even for such a short time.

Zoe, Karma's mother



Nadine's Story

Hazel died aged 13 weeks

On the 9th June 2021, I gave birth to my 4th and 5th babies, my second set of twins.

I had a healthy and textbook pregnancy, both babies grew as they should and were delivered at 37 weeks and 3 days. We came home the next day with our completed and happy family.

Fast forward 13 weeks and 6 days, we enjoyed a wonderful day at our local play cafe with Hazel's nanny, her brother Cody, and her twin sisters Olivia and Ivy. We came home, gave her and Cody their evening baths, snuggled them up and let them sleep in their pods on the sofa whilst we watched television. At 11:30 pm, we took them up to their cot, changed their bums and settled them for the night. Hazel woke, cooing, smiling and wriggling all over as she always did.

We went to sleep peacefully and happily, until 3:15 am, when Cody cried for his dummy.

Phil (my fiancé), put the dummy back and noticed Hazel had rolled onto her front, something she'd just learnt to do!

He turned her onto her side, her favourite way to sleep, and noticed a stillness. He scooped her up and woke me shouting that she wasn't breathing. I pushed on her chest and shouted her name, shaking her slightly in the hope she was in deep sleep. I knew this wasn't the reality, as she was freezing cold, white, and completely limp.

I called 999, screaming down the phone that she wasn't breathing. Phil's parents live a minute's walk from our house, thankfully, so Phil ran with her in his arms to his dad who is a retired firefighter in the hopes he could save her.

When I made my way around with Cody, leaving the 3 other girls fast asleep in bed, I arrived to see her grandad performing CPR. An ambulance arrived not long after, even though it felt like a lifetime, they took her into the ambulance and began working on her.

By this time, Phil's mum had run round to our 3 other girls and the police had arrived at both Phil's parents' home and ours.

We were blue-lighted with them to the hospital, where doctors and nurses were working tirelessly to save her, but we knew she'd been gone long before we found her.

The doctor delivered the official news and the world crashed down around us.

We spent 3 and a half hours with her, in and out of the room between tears and distress. The hospital looking after us and her every step of the way, until the local detectives arrived to go through the course of events. As they should, many questions were asked regarding what had happened, and her body was checked for any marks. Crime scene investigators were in the house for most of the following day and removed the mattress, blankets and comforters that were in with Hazel at the time.

It was surreal, to say the least.

Once we'd said our final goodbyes, we left the same hospital without her that we'd left just 13 weeks and 6 days before with her and her brother snuggled into their car seats.

We have a beautiful memorial table for Hazel in our living room, so her sisters can always see her happy and smiling. They often chat to her photograph and leave drawings and notes for her there too.

We are yet to reach her birthday or the anniversary of her passing, but we plan to let her sisters and eventually Cody buy a small gift to go into her memory box each year. We will also release eco-friendly balloons, as her big sister Isla's first question to us after finding out Hazel had passed was "How will Hazel get her cards, or see her balloons if she is in heaven?".

After understanding the work The Lullaby Trust does first-hand, I've wanted nothing more than to help raise funds to help keep their services available to families like ours. And to fund the all-important research they do in the hopes of one day finding a way to detect and prevent the tragedy that is SIDS.

We have joined in with Bake it for Babies by holding a tabletop sale and raffle at a local pub; left donation boxes at local shops and pubs; had a donations box at Hazels funeral service; and we are currently planning a Tots PJ party, coffee morning and a climb of Ben Nevis! As a family this has given us something positive to focus on throughout, and we hope that any funds we raise will be able to someday stop other families having to go through this awful experience.

Nadine, Hazel's mother



Jennifer's story

Jessica Rose died of SIDS, aged 10 months

Jessica Rose was born in March 2014, just two years younger than her big brother Jack. We couldn't believe how lucky we were to have a baby girl, "one of each" was more than we'd dared to hope for and we felt like we had the world in our arms when she arrived to complete our family.

I had a completely normal pregnancy, a relatively quick and straightforward delivery and Jessica thrived and met her milestones, just like her big brother had done before her. I felt so relaxed second time around, as I knew what I was doing this time!

When Jessica was 10 months old I returned to work part-time. She started to attend the same nursery as Jack and from experience, I knew to expect a few months of sickness as she shared germs with the other children.

On Wednesday evening I finished work and went to collect Jessica to find she had just fallen ill as I arrived. I took her home and she wasn't interested in her milk, or anything to eat so I decided to run her a bath to relax her and get her to bed so she could rest.

Jessica was always a light sleeper, she would often wake during the night and cry for a moment before going back to sleep, sometimes my husband or I would go in to comfort her if she needed reassurance. At around 5 am she woke and cried, she shared a room with Jack so James went in to give her a cuddle and settle her down. I heard her give her usual murmurs and go back to sleep, James came back to bed and we all settled down again.

At 6 am Jack leapt out of bed as he does every morning, full of energy and running across the room! I jumped up quickly and pulled their bedroom door shut, relieved that he hadn't woken Jessica as being poorly she would need her

rest. We went downstairs, made a cup of tea and watched the Thomas the Tank Engine DVD Jack had received for his birthday, a couple of weeks earlier.

James went upstairs to brush his teeth and get ready for work. When he reached for his toothbrush he knocked over the pot containing the brushes and it clattered into the sink. Concerned that he didn't hear Jessica stir following the loud noise he went to check on her. On opening the bedroom door he found her face down in her cot and unresponsive. James rushed downstairs with her whilst calling my name and I ran to the door, to find him stood with her in his arms, her face and body were limp, we were terrified.

James passed her to me and made the 999 call, as he gave our details to the operator, I carried her to the hallway and laid her down flat on the carpet, taking her out of her sleeping bag and opening her mouth to check her airways. I couldn't find any obstructions but she wasn't breathing. At that point, James took over and started to give CPR on the instructions of the emergency operator whilst we waited for the ambulance to come.

I called my Mum and asked her to come straight away to look after Jack. Whilst we waited for the ambulance I clutched Jack close and sobbed "Please come, please come and fix it". When the ambulance arrived we rushed to the hospital and they took her to the resus room. They started to hook our tiny baby up to numerous cables and monitors and worked.

They said we could watch but we went to the relative's room to wait, I knew deep down what the outcome would be. After a while, we were called back in and the doctors explained that they were having no success and they called the time of death whilst we were in the room. It was like watching a TV show, it was so surreal.

Afterwards, we weren't allowed to go home. We handed over our house keys to the police who had to be involved as it was a sudden death of a child. When we did go back we found them searching and photographing the whole house. They took some of Jessie's things away in evidence bags, it was so upsetting, all we wanted was to be alone to process the shock of what had just happened.

Very soon after Jessica died we were given details of The Lullaby Trust and a local bereavement charity called the Bluebell Foundation. Knowing that Lullaby was there was such a comfort, I would often read stories and information on the website whilst I tried to process what could have happened to our little girl.

It took 8 months to receive the results of Jessica's post-mortem, which delivered the expected verdict of SIDs. Although not knowing a reason for her death was hard to deal with, we knew we had done nothing wrong and followed all the safe sleep guidelines. Maybe one day an answer will be found, which is why we choose to support Lullaby with monthly donations and are helping with the latest research scheme.

6 months after that morning, we fell pregnant again and in March 2016 we welcomed another beautiful little girl into our family, Juliet Joy. Whilst losing Jessica has been our worst nightmare, in many ways, it has made us stronger. We no longer worry about the small things, we do what makes us happy and we don't for one moment take what we have for granted.

We will always have 3 children, just one isn't here with us at home, however she is firmly tucked inside our hearts and will forever be a part of our family.

Jennifer, Jessica's mother



Katie's story

Archie died on the 2nd of June 2014, aged 6 ½ months


My brother Tom died 18th December 1986 at 7 months old. I wasn't born until 2 years later. I've always known about Tom. There was never a definitive moment I can remember of being told about his death, he was always kept as part of the family. We normally get together on his birthday and the anniversary of his death. We keep his memory going by talking about him, what he liked doing, how close he was to my dad and with the photos we keep around the house.

In 2013 I fell pregnant with Archie. It was a typical pregnancy until about 2 weeks before I was due to have him. At a routine midwife appointment, I was told I had to go to the hospital as my blood pressure was far too high. They tried for over 4 days to induce me but couldn't get me to go into labour so performed an emergency C-section. Both my children after Archie have been planned c-sections

Archie was a very happy, easy-going, content, smiley little boy. He was a big baby who was active and alert. He had a laugh that sounded like a witch's cackle that we all loved.

We loved our walks. We would walk through a park in Liverpool quite a lot. I also have two brothers who had babies around the same age so we spent a lot of time visiting them. We decorated his room with the Hungry Caterpillar theme and would read that book plus the Gruffalo most days. He loved playing in his baby bouncer and would spend 20 mins at a time happily bouncing in there.

Archie died on the 2nd of June 2014 when he was 6 and a half months old. The day before he had been his normal self; we had visited my and my



fiancé's families before heading home. After hearing about my mum losing Tom and the fact Archie and Tom looked so similar I was extremely paranoid about SIDS and would have nightmares that he had died constantly. Because of this, we followed all the advice on how to prevent SIDS. We waited until he was 6 months old to put him in his own room, he slept on his back, used a dummy and we had a breathing monitor under his mattress. The only thing I couldn't do was breastfeed which I guess was because of the traumatic birth.

On the 2nd of June at 7 am my partner's alarm went off for work. As he was walking past Archie's room his breathing alarm went off. I heard my partner say 'You ok mate?' And then he started screaming and I knew what had happened. He brought him into our room and he was blue and unresponsive. I tried to wake him up while my partner rang an ambulance. At the time we lived very close to Alder Hey Hospital and they were there within 10 minutes. They took him to hospital and worked on him for about an hour but they never got him back.

After speaking to the pathologist weeks later, we were told there was no reason he died that they could find. He was perfectly healthy and they couldn't find any reason this had happened.

I didn't cope very well after his death. Immediately afterwards I remember begging the doctor to go back in a save him, screaming at the person who tried to take him off me as I was told he needed to go in the fridge. I remember my brother saying to my mum 'Make her stop making those noises, she sounds like you did'. He was 3 when they lost Tom, my other brother was 6 so they were living childhood traumas again.

Since this has happened my partner has had two strokes due to stress, the first one was about 5 months after losing Archie. My mum is still on antidepressants after that day. I refused to take any pills and had quite in-depth counselling which helped me massively.

On the date of what would have been Archie's 2nd birthday, we found out I was expecting my little girl Pippa. Although this was an extremely worrying time she helped us all live again. Then on Archie's 5th anniversary of his death, I found out I was expecting again and we had Charlie 2 weeks ago!

I was in touch regularly with The Lullaby Trust when Pippa was born. Both she and Charlie are part of the CONI scheme where we were given a breathing monitor and CPR training. Charlie also wears a monitor to measure his blood oxygen levels and heart rate which is helpful.

CONI has been great. When I had concerns about Pippa we were seen by a doctor straight away, which was a massive help as we were both so paranoid that the same thing might happen to her. I'm sure we will have scares with Charlie too but it's comforting to know we have the same help available.

Kate, Archie's mother, and Tom's sister



Annie's story

Hazel died when she was 6 months old

I was only 16 when I found out I was pregnant and had recently broken up with her father so it was really scary. I had sickness for the first 18 weeks and ended up hospitalised with E.coli at around 5/6 months which nearly caused me to miscarry, so not the easiest pregnancy.


My daughter arrived one day before her due date after 5 days of slow labour followed by 4 hours of active labour. She was born completely naturally at Bradford Royal. I named her Hazel Eve.

When I first saw her I thought that I had never seen anything so precious in my life. I knew what my life was for now. I was absolutely meant to be a mum.

24 hours later we went home. Due to family pressures on both sides I actually ended up back with Hazel's dad and living with him when she was born so he was around to help. My mum came and helped us a lot too as he worked shifts so when he was on nights she stayed with us.

Everything was just a blur of nappy changing and breastfeeding. I was so determined to prove to everyone that I wasn't going to be a stereotypical teen mum that I tried to be superwoman instead.

A year later, we went on a day trip to a farm with the local children's centre. She spent the morning chasing roosters and stroking guinea pigs and having a brilliant time. After we got home I put her in her cot for her 5 pm nap, the same as every day while I made her tea. I went to get her at 5.30 pm and she was blue.




I had the monitor with me the entire time, there wasn't a single warning sign. I pulled her out of her cot, called 999 and started CPR. I'd done infant first aid when she was about 6 months old as she'd had a nasty chest infection. The operator kept count for me and I didn't stop until the paramedics were over me ready to take over without missing a beat. As soon as she was in their hands I fell apart, screaming and crying and begging her to wake up.

We were taken in the ambulance and blue-lighted to the hospital. Her dad worked there so met us at the entrance as we went into resus.

They tried to resuscitate for about 40 minutes. They kept telling me that the machines may show something but that it didn't mean anything, it could be what they were injecting her with, I just kept begging her to wake up. When they stopped they said that they had tried everything they could for as long as they could, but it was time to let her go.

I was allowed to sit with her and hold her. I spent about 2 hours telling her it wasn't a funny joke, that she had to wake up now, that I needed her to wake up.

When I was finally taken home I couldn't go into the house. I couldn't face it. My family was all abroad so we ended up staying with my in-laws. I had a strained relationship with them so spent the night in silence staring at the ceiling making deals with the universe so that when I woke up she'd be back with me and it would all have been some cosmic mistake. My family flew home as soon as they could and other family members travelled over from further afield to make sure I wasn't alone.



The next morning I threw myself into planning a funeral as beautiful as my baby girl was. We had an outdoor ceremony. I read the poem I said to her every night, the mums from her playgroup all sang her favourite song with me, and I hand-folded 3,000 pieces of butterfly confetti, so that everyone that came could scatter it over her instead of soil, so they fluttered as they fell.

It wasn't until four months later in August that we had the official hearing after the inquest. There was a man sitting in the pews that looked official and never introduced himself to the family as we went in. My dad actually asked him who he was afterwards and it turned out he was from the local paper, they were going to print Hazel's cause of death without even telling us. I spent the next 24 hours calling the paper and essentially attacking their social media trying to stop them, but they still did it, just without her name. I felt violated.

Having an actual cause, hearing it said out loud that there was absolutely nothing I could have done gave me a little peace, but didn't completely convince me that there wasn't something I could have done, a way I could have known what was going to happen and prevented it.

When I fell pregnant again with Ivy Olivia, I was absolutely terrified, even though it was a planned pregnancy.

There's not a wall or surface in our house that doesn't have photos of Hazel on it. Ivy knows who she is and we tell her all the stories about her sister. I have her handprint tattooed in the same spot between my tummy and ribs where she put her hand through my muscles when I was pregnant. We have windmills in the garden and whenever they spin we tell Ivy that that's Hazel saying hello. I light a lot of candles and talk to her when the flame flickers I know she's listening.

Annie, Hazel's mother



After thirty six years

Simon died in November 1974, aged 2 months

My son Simon died suddenly and unexpectedly in November 1974 at the age of two months. Thirty-six years on I find that I often think about him and a physical sense of his absence remains. It seems to me that over the years my grief has taken this pattern. Immediately after Simon's death, there was numbness; it was difficult to absorb the fact of his death. Then followed a period of disorganisation when I felt consumed with feelings and it seemed unlikely that I would ever again be able to engage with everyday life. Since then there has been a time of integrating Simon's death into my life and I see this phase as a continuing one. This continuing nature of my grief has led me to reflect on the often-quoted view that "normal" feelings of grief last for about two years.

Actually, I think parents are allowed to grieve profoundly for about nine months and then be tearful for up to two years. Beyond this time showing feelings may result in being told by others that you have not grieved properly. In contrast to this, I believe that you grieve in proportion to the emotional space that the dead person has occupied in your life. A child or other special person occupies such a large part of your emotional space that a loss of this magnitude can be felt for as long as you are there to feel. I am emphasising the long-term nature of my grief because I feel that after two years a subtle process occurs in which permission for parents to be open about their grief is withdrawn and what I feel is perfectly normal behaviour can become pathologised. This perspective caused me to hide my feelings for many years and added to the burden.

At present, there are three things that I find especially helpful. Firstly, I keep a sense of connection with Simon through one of his toys. In the early days after his death all his things were removed from the house. This was done by well-meaning people but I was not consulted. Fortunately, the bathroom was omitted from this tidying up and I was able to secure Simon's small yellow duck. The duck now sits on my bath and it enables me to maintain a daily connection with him.

The second thing is contained in my reply to the unavoidable question "How many children do you have?" For many years I have said "Two daughters and I also have a son but he died when he was small". You will note I say

have have rather than had. I have given up worrying about how this may be received. If I am going to have a meaningful relationship with the person they need to know that this is important to me.

Thirdly, I talk to people about Simon when I need to. I find talking to other bereaved parents especially helpful. With them, I can be myself and not worry about what I say. Their natural acceptance is deeply therapeutic and the best form of help that I have encountered over the years.

These are my ways of integrating Simon into my life and they enrich it. Others will find different ways. Overall I feel happy and content and secure in the belief that it is possible to live with such a loss.

Dee, Simon's mother

Will I always feel like this?

“At the time of bereavement, you feel like the world is crashing down. But in time, with love and support, you learn to deal with it and it’s OK to cry. The main thing is to not be afraid to talk about your child. Keep their memory alive!”

Sam, Olli’s mother

“The heartache is still ever present but is more of a dull ache nowadays, ever-present but easier to live with. Alexander is still a very large part of our family, we fundraise in his memory and as a family, we are creating a legacy on his behalf. I would change what happened to us in a heartbeat but I can’t so we carry on with our new ‘normal’ and I’m proud of what we have been able to achieve in Alexander’s name.”

Nicola, (twin) Alexander’s mother

“Annie was born 7 weeks early which looking back was a blessing, as we were able to have more precious time with her. It still hurts, and part of me wants it to hurt, but even though it does, I’m always left with a smile as I think of how lucky I was to have such a beautiful daughter even though it

was for only 600 days.”

Neil, Annie’s dad

“Every day for me had been a struggle emotionally and physically. Body, mind and soul are wounded so deeply and the pain is so intense and isolating you wonder whether you will survive it... [Now] I can say I feel very proud to have been given an angel for 14 months. I want to share Joseph and celebrate his life and love and the experience he gave me to give hope to others who are in desperation.”

Georgia, Joseph’s mother

“My son has taught me how to value all that life has to offer, and to appreciate the beauty in small things. Since he is not able to, I have resolved to live my life with vivacity and enthusiasm, and to enjoy every moment ...I am proud of the lessons that my son taught me during his all too short life.”

Helen, Yanni’s mother



Is it normal to feel guilty?

“One challenging part was being at the hospital being made to feel like I was a criminal, like myself or my husband had done something wrong or it was our fault. I understand the police had a job to do and Darcey was evidence but to us, she was our little girl and being told we weren’t allowed to touch her until the inspector had been was heart-breaking. 8 years on and we still don’t understand why she passed away and why it was us. When she had a post-mortem they told us there wasn’t anything wrong and she was a healthy, happy little girl who fell asleep and just never woke up.”

Zoe, Darcey’s mother



“I can still recall smiling at something silly on the television for the first time weeks after

and feeling the biggest pang of guilt, questioning how on earth I can smile, and how will I smile ever again? But as each day, each week, each month passed slowly things became slightly less painful.”

Michelle-Mia’s mother

I feel so alone:

“We may feel alone but there is comfort in the knowledge that we are not, and with the help of FSID (now The Lullaby Trust), and the experience and gift our babies gave us, we can hold up the torch and burn it brightly in what may seem a dimly lit society.”

Georgia, Joseph’s mother

I’m frightened my baby’s siblings will forget

“She opened her purse and to my surprise showed me a photograph of Nicola in her baby chair which she had taken out of the album. She suddenly felt the need to have a photograph of her sister with her...I was so pleased that Sarah had felt she could take one.”

Ann, Nicola’s mother.

“When I was seven, I won a prize for a poem I wrote at school. I don’t remember the exact words but it was about a star and the last word was ‘please?’ written in big pencil letters. I wished on that star to meet Thomas – the big brother I had never known, but who, in my mind, was the coolest big brother anyone could wish for.”

Ellie, Thomas’s sister

Who will understand?

“Luckily, I got lots of support from my friends and family. I also tried counselling but I found at the time that it just wasn’t right for me. The Lullaby Trust offered me a Befriender who really helped me a lot. My Befriender was older than me, but the memory of her son was still very much alive. Through speaking to her I learned that it’s okay to have off days long after your bereavement, and that over time it gets better.”

Sam, Olli’s mother



“Although my close friends and family were supportive, no one knew exactly how I was feeling. The ‘what ifs’ were endless.

I contacted The Lullaby Trust the following February. The lady on the end of the phone was lovely, I could say exactly how I was feeling, I didn’t have to worry about upsetting anyone else or hold back from my feelings of utter despair.”

Joanne, Ryan’s mother

“A couple of days later I made the call... I do not remember the conversation in its entirety, but I do remember the lady telling me that this was not my fault, and tried to reassure me. I couldn’t talk for crying, every word was a sob but she was there, on the end of that telephone with me for what seemed like an eternity. Everything I was scared to say to my husband, my parents, my sister and brothers, my son, because I didn’t want to upset them further, I poured my heart out to her. I was broken. That lady saved my life that day. She was there. This stranger, who knew nothing about me. She cared and took my call.”

Wendy, Peter’s mother

“It was good to talk, both to someone who was trained to talk, but also to another mum that had felt the desperation that I was feeling at the time. I was also referred by my GP to a specialist bereavement counsellor, I had 12 sessions with her that enabled me to see things more clearly.”

Emma, Daniel's mother

Is The Lullaby Trust Support time limited?

NO

“Life is full of variables but one thing that is always constant, in my life at least, is The Lullaby Trust. During the long periods of soul searching over the past decade, I was always able to rely on the charity as being a source of great support. It has helped me to build strength and gain a different, positive, focused outlook in life and I am truly thankful for the outlet that the charity has provided me.”

Abir Charlie's father

Lullaby Trust support

BEFRIENDERS

All bereaved families who contact us are offered support from a Befriender. Befrienders are trained volunteers, who are themselves bereaved parents, grandparents and other relatives. Befrienders offer personal support by phone or email for as long as needed.

HELPLINE

Our helpline is here for anyone affected by the sudden and unexpected death of a baby or young child, whether it was recent or very long ago. The helpline is open 365 days a year, at the times detailed below. The Bereavement Support number is: **0808 802 6868**. Calls are free from all landlines and most mobile phone networks. Our Bereavement Support Helpline is open every weekday from 10am–2pm and every weekend and on public holidays from 6pm–10pm in the evenings. All calls are answered personally, by experienced advisory staff during office hours, and at weekends and public holidays by trained volunteer Befrienders who have themselves experienced the sudden death of their baby or young child.

THE LULLABY TRUST WEBSITE

The Lullaby Trust's website www.lullabytrust.org.uk has a bereavement support section with advice and resources for bereaved families.

EMAIL AND SOCIAL MEDIA

We also offer support by email at: support@lullabytrust.org.uk or you can message us on Facebook www.facebook.com/LullabyTrust or Instagram

Bereavement Support Facebook Group:
<https://www.facebook.com/groups/382346555850908>

IN MEMORY WEBSITE

Our In Memory site offers bereaved families the chance to create an individual memorial page for their child, where you can share memories, thoughts and stories with family and friends, as well as light candles, add music, photos and videos. It's simple, quick and free to create a memorial page at lullabytrust.org.uk/tribute .

FAMILY DAY

The Lullaby Trust organises free family days every year, where bereaved families can enjoy time in relaxed surroundings, and if they wish meet and talk with other families and Befrienders. They are held at places such as a theme park or country venues in England, Wales and Northern Ireland.

To find out more about these days please contact us on [0808 802 6868](tel:08088026868) or to register your interest for a family day in your area email support@lullabytrust.org.uk

Thank you to those families who have written and given their stories to The Lullaby Trust for inclusion in this booklet.

CARE OF THE NEXT INFANT (CONI)

For families whose baby has died suddenly and unexpectedly, we understand that having another baby can be an anxious time. The CONI programme, run in partnership with the NHS and local health visiting providers, offers extra emotional and practical support. Additional visits from health visitors, symptom diaries, weight charts and the loan of movement monitors, which pick up movements as the baby breathes, can help give reassurance and confidence to families. It is important to mention that unfortunately the CONI programme isn't available everywhere and can differ between areas. This depends on whether the programme has been commissioned as part of the local health visiting services. Parents can call our Bereavement Support Helpline to see if CONI is available in their area.



For bereavement support:

Call: **0808 802 6868**

Email: **support@lullabytrust.org.uk**

Visit: **www.lullabytrust.org.uk**

The Lullaby Trust provides support to bereaved families, expert advice on safer sleep for babies; and raises awareness of sudden infant death.